VOICE OF THE DIABETIC

A SUPPORT AND INFORMATION NETWORK

The Diabetics Division of the National Federation of the Blind

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My transformation

by Betty Walker

Betty Walker shares her dialysis and kidney transplantation experiences.

I was born in 1953 in Dover Plains, New York. In spite of the fact that I was diagnosed with diabetes at age five, my childhood was more or less "normal." I graduated from high school in 1971, and earned an A.A.S. degree in Nursery Education from Duchess Community College in Poughkeepsie, New York. My problems began at that time.

Glaucoma and diabetic retinopathy took my sight before the end of 1974. In January of 1978, I was confronted with renal failure as well. After coping with losing my sight, which I did by daily thanking God for each day, I felt this new development was just another of life's hurdles that I had to jump over. If I could not jump, I would climb; no matter how slowly I would have to climb.

When I went on hemodialysis, most of the time I felt very ill. I was so nauseated that I could not eat. My social life was nonexistent, and I no longer enjoyed any hobbies. I was so tired that most of the time between dialysis sessions I spent in bed. Life went on like that for about six and one half months. When I decided to have a kidney transplant, I figured I had nothing to lose. Dialysis was always there to fall back on.

On July 13, 1978, I was "born again." My mother, Fran Bator, gave me life when I was born and gave it to me again when she became my kidney donor. The transplant was done at Yale-New Haven Hospital. It should be called a "transformation," because that is what it was for me.

I could hardly believe it, but, the day after the transplant, I wanted to eat! I was told that I had to wait one more day. Given Jello and ginger ale the next day, I told the doctors I wanted "real" food. The following day, request granted, I ate like a horse, devouring every bit of food on my tray. I felt like running or doing something to release my energy. My hematocrit rose from 12 to 40. All of my blood chemistries were now normal. The only problem was with my blood sugar, which had risen because of the steroid I was prescribed as postoperative medication.

The most frustrating thing for me was that I could not take a shower or a bath until my stitches were removed. Wouldn't you know it — they left them in for sixteen days! As soon as the doctor removed the stitches and was out the door, I was in the shower.

Since I became blind I have had this philosophy: I never say something CAN'T be done unless first I try it and know that I can't do it. So far the only thing I've found I can't do is drive a car.

I lead a fairly active life since my transplant. My favorite leisure activity is horseback riding. Yes, it can be

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Voice of the Diabetic *is a national publication of The Diabetics Division of the National Federation of the Blind. It is read by those interested in all aspects of blindness and diabetes. We show diabetics that they have options regardless of the ramifications they may have had. We have a positive philosophy and know that positive attitudes are contagious!*

News items, change of address notices and other magazine correspondence should be sent to:

Ed Bryant, Editor
Voice of the Diabetic
811 Cherry St., Suite 309
Columbia, MO 65201-4892
Phone: (314) 875-8911

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Renal failure, dialysis, and transplantation

by Ed Bryant

Many long-term diabetics face the prospect of kidney failure, called End Stage Renal Disease (ESRD). For them, there are three options for treatment. In *hemodialysis*, the patient's circulatory system is temporarily linked with a machine that performs the blood-cleansing functions of the human kidney. In *peritoneal dialysis* a tube is inserted into the patient's peritoneal cavity, allowing urine and unneeded body fluids to periodically drain from the body. The third option is kidney transplantation, in which a donated kidney is surgically implanted into the patient's body.

Some people, due to pre-existing medical conditions, cannot have a transplant, and others do not want one. A diabetic on hemodialysis can survive by closely adhering to the many rules that must be followed to correctly dialyse or filter the system. On hemodialysis, patients must follow rigid diets and must spend a great deal of time hooked to the machine. Some patients find the procedure quite painful.

According to U.S. Renal Data System (USRDS) figures, there are more than 189,954 kidney patients undergoing dialysis in the United States today. HCFA statistics show that about 30% of them are there because of diabetes complications, and about 40% of those commencing dialysis or seeking a transplant at this time are diabetic. Some remain on dialysis long-term; others make use of the process while awaiting a kidney transplant. As an aside, before 1980 few diabetic ESRD patients were dialysed; they simply sickened and died. Those who did dialyse faced a high mortality rate. Medicine has come a long way since then, and the odds have improved with the options.

Dialysis is not an "artificial kidney." A person undergoing hemodialysis must be hooked up to a machine three times a week, three to four hours per session. A normal vein cannot tolerate the 16-gauge needles that must be inserted into the arm during hemodialysis. The doctor must surgically connect a vein in the wrist with an artery, forming a bulging fistula that will better accommodate the large needles needed for treatment.

Long-term diabetics often have cardiovascular and blood pressure problems, and the added strain of dialysis, with its rise in blood pressure straining eyes and heart function, can be too much for some. The diabetic dialysis patient spends, on the average, 30% more time in the hospital than does the non-diabetic dialysis patient, according to USRDS figures.

Some patients choose CAPD (continuous ambulatory peritoneal dialysis) or its variant, CCPD (continuous cycling peritoneal dialysis), both of which can be carried out at home, without an assistant. CAPD works inside the body, making use of the peritoneal membrane to retain a reservoir of dialysis solution, which is exchanged for fresh solution, via catheter, every four to eight hours. CCPD makes use of an automated cycler, which performs the exchanges while the patient is asleep. Although more complicated and machine-dependent, it does allow daytime freedom from exchanges, and may be the appropriate choice for some. Though the risk of infections is heightened (as it is with any permanent catheterization), these two processes have advantages, one being that insulin can be added to the dialysis solution, freeing the patient from the need to inject, and giving good blood sugar control. Another advantage to peritoneal dialysis is the accessibility of the process for blind ESRD patients. "When blind or visually impaired people become familiar with the system, and can do it well and efficiently, they're no more at risk than anyone else" states certified nephrology nurse Lois Schmidt.

Kidney transplantation is a logical alternative for many. It substantially improves a patient's quality of life. Although the transplant recipient must be on anti-rejection/immunosuppressive therapy for life, with the inherent risk from otherwise nuisance infections, a transplant frees the patient from the many hours spent on hemodialysis procedures each week, or from the periodic "exchanges" and open catheter of CAPD, allowing a nearly normal lifestyle. For those ESRD patients who can handle the stresses of transplant surgery, the resulting gains in physical well-being

(Continued on page 4)

Table 1
The Ten Most Active Renal Transplant Centers

Center	# transplants	% success	% expected
1. Univ. of Alabama Hosp. Birmingham	522	75.7	79.4
2. Univ. of California Hosp. San Francisco	521	77.0	81.0
3. Presbyterian Univ. Hosp. Pittsburgh, Pa.	453	72.2	77.0
4. Univ. of Wisconsin Hosp. Madison	433	89.1	80.8
5. St. Vincent Med. Ctr. Los Angeles, Calif.	393	73.3	80.8
6. Univ. of Minnesota Hosp. Minneapolis	386	83.2	81.5
7. California Pacific Med. Ctr. San Francisco	344	79.8	78.3
8. Ohio State Univ. Hosp. Columbus	316	81.8	80.5
9. Shands Teaching Hosp. & Clinics, Gainesville, Fla.	303	77.9	78.3
10. Tampa General Hosp. Tampa, Fla.	279	77.9	77.0

Source: UNOS, "1991 Report of Center Specific Graft and Patient Survival Rates," published 1993.

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Renal failure, dialysis, and transplantation

(Continued from page 3)

add up to real improvement in quality of life and overall longevity.

If you have decided to pursue the transplant option, you should know that now, for the first time, there has been a comparative study of all transplant centers in the United States. The Organ Procurement Transplant Network (OPTN) is a federally mandated information system linking transplant donors with recipients, and the United Network for Organ Sharing (UNOS) is the agency maintaining that database. Between October 1987 and December 1989, UNOS surveyed graft-survival and patient survival (success) rates at all of the 219 transplant centers in the U.S., recording age, race, first vs. repeat transplant, living relative vs. cadaver donor, etc. UNOS data allowed a tighter definition of "success." Statisticians pooled all the data, and developed "expected survival rates," then compared each center's performance to its "expected" figures, which were derived from profiling the age and relative health of the patients at that center.

Some centers weren't as good as they claimed to be. Some beat the "expected" figures by comfortable margins. Some "improved" their performance by not accepting older or high-risk transplant candidates. Some centers resisted providing UNOS the requested data.

UNOS data reveal that, during the time surveyed, the ten centers listed in Table 1 carried out the most kidney transplants. The critical measure was "graft success", whether or not the transplanted kidney was functioning at the end of the test period. How well did the centers do? Data presented in the table reflect percentage of transplanted kidneys serving their recipients well twelve months after transplant surgery.

As UNOS obtained report statistics for every transplant center in the U.S. at the time of the survey (and another such survey has just been completed, to be published shortly), it should be possible to statistically evaluate any prospective transplant center in advance. Such information can be accessed by contacting the United Network for Organ Sharing, 1100 Boulders Park, Suite 500, Richmond, VA 23225; telephone: 1-800-243-6667. For a $7 processing fee, UNOS will provide written information on up to ten centers. They require name of center, city and state.

The report was prepared by UNOS under contract with the U.S. Department of Health and Human Services, Health Resources and Services Administration, Bureau of Health Resources Development, Division of Organ Transplantation. For information on how to obtain a copy of the report, or assistance with interpreting the data, contact: Health Resources and Services Administration, Bureau of Health Resources Development, Division of Organ Transplantation, 5600 Fishers Lane, Room 11A22, Rockville, MD 20857; telephone (301) 443-7577.

UNOS cautions the reader that statistics are more a reflection of past performance than a guarantee of future performance, and that the most significant number is the deviation between expected and actual success rates. Did a given center do as expected, better, or worse? That figure should say something about the program. Not all variables could be mapped; there was, for instance, no way to model the effects of patient noncompliance. Not all centers admitted patients with the same degree of health and some appeared reluctant to perform transplants on "high-risk" patients.

Statistics should not be worshipped. Talk to your prospective transplant center. Check them out thoroughly. It is *your* body; what matters is are they right for *you*?

I and others knowledgeable in kidney transplantation advise you to pick the best transplant center possible. Once you have read their statistics, ask your prospective center the following questions. If they don't answer to your satisfaction, you should consider going to another center.

1. Do you have an information packet for prospective donors and recipients?
2. Can you put me in touch with someone who has had a transplant at your center?
3. What is your "graft survival" (success) rate?
4. Who will my transplant surgeon be? If a fellow or resident, will he/she be supervised by a practicing transplant surgeon?
5. How long have your *current* surgeons been doing kidney transplants? How many have they

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Nicole Gemignani, a kidney transplant recipient from Nimes, France, drew this illustration to depict how much better people feel after escaping dialysis through kidney transplants.

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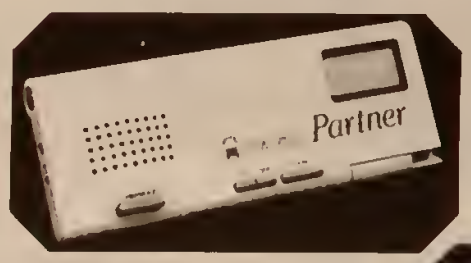

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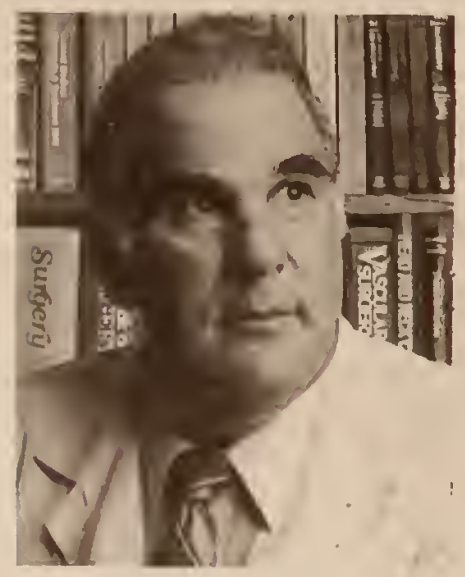

John Najarian M.D., Chairman of Surgery at the University of Minnesota, is interviewed regarding kidney transplantation. Dr. Najarian has overseen more than 3500 kidney transplants, many for diabetic recipients.

*From the **Voice** Editor: The following is a transcript from the television show "Physicians' Journal Update", which aired December 6, 1992, and featured Dr. John Najarian, Chairman of Surgery at University of Minnesota Hospital. A pioneer in kidney and pancreas transplantation, Dr. Najarian has overseen more than a thousand kidney transplants for diabetic patients.*

The University of Minnesota Hospital has been in the forefront of developments in immunosuppressive/anti-rejection drug therapy for the last three decades. Many of the immunosuppressive drugs given to transplant patients today were perfected at Minnesota, and work continues on the next generation. OG 37-325, OKT4a, FK506 2, deoxyspergualin and rapamycin are several names under evaluation today, perhaps to become the next generation of anti-rejection drugs.

Dr. Najarian pioneered kidney transplantation for diabetic patients. He began transplants for these patients at a time when the majority of the transplant community said it was too difficult. He proved that diabetics had the same transplant survival rates as nondiabetics.

Incidentally, I am diabetic and had a successful kidney transplant more than 10 years ago. I cannot begin to tell you how much better I felt after receiving my transplant as opposed to being on dialysis.

Announcer: **A visit with kidney transplant pioneer Dr. John Najarian.**

Dr. Tom Linden, co-anchor: When it comes to renal transplantation, there may be no physician better than John Najarian, Chairman of Surgery at the University of Minnesota. Over the past 25 years, Najarian has overseen 3,500 kidney transplants, and his latest cumulative data in the December 1991 *Annals of Surgery* show an increase in five-year graft survival from 58 percent in the 1970s to 71 percent in the 1980s. At the same time, the University of Minnesota has used more cadaver donor organs and transplanted more diabetic recipients, factors formerly associated with a less favorable long-term outcome. From Minneapolis, producer Jeanne Johnson has this report.

Dr. John S. Najarian, MD: Hi Diane. Could I see Nancy's medical chart?

Diane (receptionist): It's right here.

Dr. Najarian: Thank you. How's she doing?

Reporter Jeanne Johnson: When surgeon Najarian first arrived at the University of Minnesota in 1967, the school was already a major center for leading-edge surgery, including open-heart surgery. The former Cal-Berkeley football tackle says he chose organ transplantation as his life goal because it represented a biological mountain no one had ever scaled. Today, as Chair of the surgery department, Najarian directs one of the largest transplant programs in the world, and at 64 years of age, he still operates five days a week.

Dr. Najarian: A whole field of tissue typing began about 1964/65 related to transplants. Up until that time, the only two drugs that we were using were Imuran and prednisone. These were our basic drugs that we were using to stop rejection of the kidney. We added ALG, or antilymphocyte globulin, to those other two drugs in 1966. There were improving results to the extent that we began to expand our criteria of doing transplants. We now do children down under the age of one. **The youngest we've done is six months of age and we take them up to, at the present time, about 75 years of age.**

We were fortunate to receive the first Cyclosporine here in the United States in 1979, and that has become really the backbone of our immunosupression to the present date. That made our results much better to the extent that we now can achieve 95 percent kidney survival over five years.

Johnson: But the fight to increase survival rate is far from over.

Dr. Najarian: The leading cause of death in transplant recipients at the present time is cardiovascular disease and in addition to that would be rejection.

Johnson: Another cause of morbidity and mortality is infection. The cytomegalovirus is one example.

Dr. Najarian: This disease accounted for about 30 percent infection in our transplant patients. When Cyclosporine came along, we were able to reduce that to less than 10

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percent, so that was very favorable, and then more recently, we found that with certain antiviral drugs, such as acyclovir or ganciclovir, we're able to reduce and actually even prevent cytomegalovirus disease.

Johnson: But the escalating cost of health care, about 700 billion dollars a year in this country, threatens organ transplantation. Its expense makes it an obvious target for cuts, but consider the alternative to surgery. Frank Holland is a type-I diabetic. After his kidneys stopped functioning, he began dialysis, which, for him, is now a full-time occupation, and he no longer wants a transplant.

Mr. Thomas Holland (dialysis patient): I'm sure that when I first started in '84 it was an awesome thing. I had no idea what was going to be happening and, in fact, I didn't get along with the machine real well. I remember times when I would get sick, but once they found the right levels, it just started agreeing with me and so we just finally said, 'No, take my name off the list. I'm going to stay on dialysis as long as dialysis agrees with me.'

Dr. Najarian: Every year the patient remains on dialysis costs anywhere from $30,000 to $35,000, and so that goes on as a continuum for as long as they live. If we transplant a patient, it costs about $35,000 to $40,000 to put in the kidney transplant. If we're successful, it's a one-cost affair. Then it's a cost of drugs after that, and the average cost of drugs is about $6,000 a year, so that's a far cry from spending $35,000 a year just for dialysis alone, not including the drugs they have to take.

Complications, of course, are great on dialysis because you're a diabetic, your eyesight gets worse, you begin getting neuropathies because something that people forget is that patients on dialysis are always uremic. It's not to say that transplantation is complication-free either. If you receive a kidney transplant and you have to have too high a dose of corticosteroids (prednisone) you're going to get problems with your bones, you may have to have your hips replaced, you may have cataracts and have to have your cataracts removed, but the chances are far less.

Unidentified Woman: You need to take four of these babies.

Mr. Frank Anzallone (kidney recipient): What is it?

Woman: It's called Dextrosol.

Reporter Johnson: Frank Anzallone, another type-I diabetic is lucky. After extensive testing, it was determined that his half-sister, Nancy, is a good donor, so **he will be transplanted before dialysis is ever required, which is now a growing trend.**

Ms. Nancy Sommerfeld (kidney donor): From the minute I knew that he needed it, I said, 'I'm here,' you know. He means a lot to me. He's my brother.

Mr. Anzallone: There are not words to describe how I feel about what she's doing for me. It's the most wonderful gift anyone could give you.

Johnson: But for those less fortunate than Frank who are waiting for an organ, the current national shortage is a real crisis, so John Najarian sets his sights on new and somewhat controversial ways to offset the demand.

Dr. Najarian: It's a terrible thing now. Patients are waiting for a year, a year and a half, two years and they're dying while waiting for a transplant. So we needed another source of organs — animals are obvious. Nonhuman primates you can't use. It would be the best, so we've turned our attention away from the primates which have advocates — animal advocates — to barnyard animals. The pig is an excellent animal — very few advocates. It turns out the pig kidney is a good size for a human, as is a liver. So I would guess that our best bet is going to be in the pig. Not only do you supply sustenance through its meat, but also through the possibility of its organs to be used for transplantation.

Johnson: Some surgeons also take issue with Najarian's view on offering financial incentives to recently bereaved families.

Dr. Najarian: Pay for part of their funeral expenses or reduce the inheritance tax on the person who dies. So there is a financial incentive that accrues — not something you put up in front as an inducement for them but something you do to help them. It wouldn't take long before the word got out that under these circumstances not only would it be a very important philanthropic act to have my kidneys used or my heart or liver, but in addition, in some way, I would also be helped financially.

Johnson: Whether you agree with him on matters of public policy is of little importance to this Minnesota surgeon. His true calling is working with his hands to save lives. At this early morning hour, it's Frank Anzallone's.

Dr. Najarian: Transplantation is kind of a dream I think all of us had. I mean, the fact that an organ is either not there at birth (such as a liver with biliary atresia), is damaged in an automobile accident, or is destroyed because of cancer, we shouldn't have to throw the rest of the individual away. It should be replaced and now it is. It's tremendous medicine. It's tremendous technology. It costs money. Unfortunately, we're one of the areas they point to when they say there's a high cost in medical care, but you're getting the best medical care in the world right here in the United States, and I think the gift of life through an organ such as a heart or a liver or a kidney is something that's without peer that I know of, and it's a real privilege to be a part of it.

Co-anchor Linden: For more information, please see the following articles: Schweitzer and others in the December, 1991 issue of *Annals of Surgery;* and from the January 8th, 1992 issue of *JAMA*, Evans and others and Sanfillipo and others.

And that is our program for this week. I'm Dr. Tom Linden. Please join us again next week for another Physicians' Journal Update at this time or any other time listed in your program guide.

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Renal failure, dialysis, and transplantation

(Continued from page 4)

done? That your center has 35 years experience with kidney transplants is of no consequence if a surgeon has only done fifteen in his or her career.

6. What is the average post-operative stay in your hospital?

7. When I come for my transplant, or come back for follow-ups, will there be any affordable housing for me and/or my family? (Ronald McDonald House, or other lodging with discount rates...) or will I get stuck in a luxury hotel for $90 a night?

8. How often will I need to come back to the center for follow-ups? Can my nephrologist do the blood tests and send you the results?

9. Can you recommend a nephrologist in my area? Do you correspond with this physician?

10. Do you have a toll-free number to call for after-transplant information?

11. What is your policy on people with insufficient health insurance? Will you work with an uninsured patient? What will it cost?

12. Are you prepared to satisfy my doubts? Will you show me the documents that answer my questions? Will you guarantee the price quoted?

Although kidney transplantation is major surgery, it yields major positive consequences. Although it is not an option for everyone facing ESRD, I strongly urge its consideration.

Below are a series of general questions and answers about kidney disease and options for dealing with it.

• ***Exactly what is ESRD?*** End Stage Renal Disease is the condition that results when an individual's natural kidneys have failed to the point that either dialysis or transplantation is necessary to maintain life.

• ***How long can the donated kidney last?*** With proper care, decades.

• ***What is done with the old kidneys?*** Damaged or non-functioning kidneys are usually left in place. For protection, the donated kidney is placed in the pelvic area, near the bladder.

• ***What is the success rate for kidney-transplant surgery?*** According to the "United States Renal Data System 1993 Annual Data Report", published by the National Institutes of Health, about 75% for a cadaver-donated kidney, better than 90% with a kidney donated by a living relative, with an overall success rate of better than 85%, better than 90% in some centers.

• ***What percentage of type I diabetics will face ESRD?*** Current statistics suggest 20%.

• ***Must the ESRD patient be on dialysis before being considered for a transplant?*** NO! University of Minnesota Transplant Center recommends that once your physician has determined that kidney failure is on the way, further delay could be harmful. The more time spent subjecting your body to the toxic excesses of kidney failure and the strains of dialysis, the greater the risk of serious complications like retinopathy and cardiovascular (heart) degeneration.

• ***How young is too young for a transplant? How old is too old?*** University of Minnesota Transplant Center statistics show a wide age range for transplant patients; from age 6 weeks to age 78 years. Individual fitness for a transplant is based on both physical condition and chronological age.

• ***Is transplantation less likely to succeed because the patient is a diabetic?*** The success rate for diabetics needing kidney transplantation is approximately the same as for non-diabetic transplant recipients. People with diabetes tend to take better care of themselves than does the general public.

• ***Who or what is the "ideal donor"?*** According to the University of Minnesota Transplant Center, for any given recipient, the closer the genetic match, the better the odds for a successful transplant: twins, siblings, relatives, friends, cadavers, in descending order of preference. The doctors will test for sufficient "genetic match."

• ***Will a donation of one kidney be sufficient?*** A single donated kidney will be entirely sufficient, and its recipient will enjoy the same longevity as the general population.

• ***Is kidney transplantation covered by health insurance?*** Medicare, Medicaid and many private insurance carriers will fund a kidney transplant. If you are uninsured, the transplant center should be willing to work with you.

• ***My transplant center is a long way away. Is there any assistance available with travel-related expenses?*** The American Kidney Fund, 6110 Executive Boulevard, Suite 1010, Rockville, MD 20852; telephone: 1-800-638-8299, has funding available for individuals who meet their assistance criteria. As part of their regular financial aid program for kidney patients, the Fund assists with treatment-related items: transportation, medication, special diet expenses, etc., up to a maximum of $200. Patients should

(Continued on page 13)

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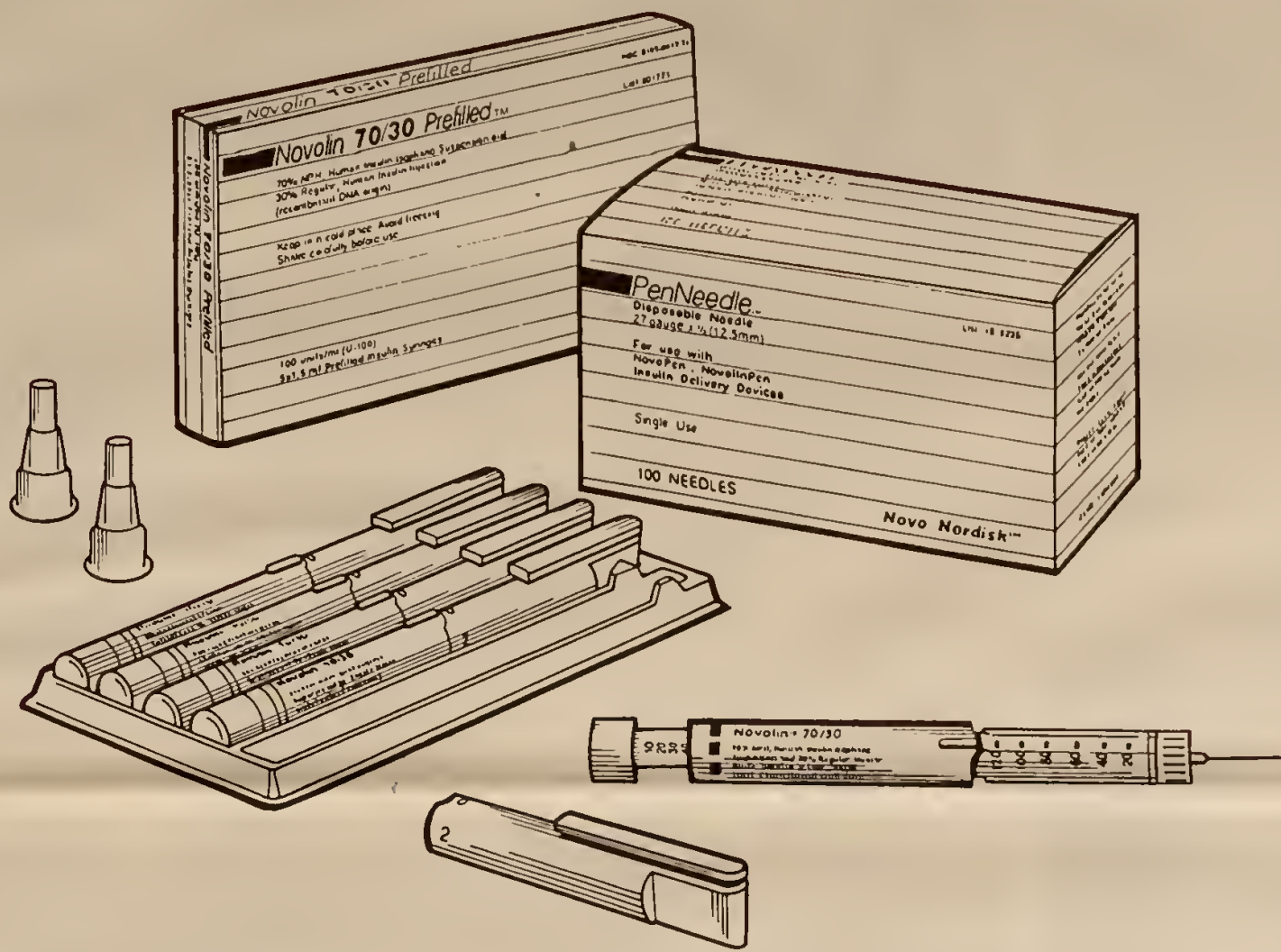

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Common heart drug may reduce kidney failure

by Peter Nebergall

A recent issue of the *New England Journal of Medicine* announced a study in which Captopril, a common blood pressure medication, significantly reduced diabetic kidney degeneration. The study, directed by Dr. Edmund Lewis of Rush-Presbyterian-St. Luke's Medical Center in Chicago, involved 409 type I diabetics in 30 U.S. and Canadian medical centers.

Based on these findings, a U.S. Food and Drug Administration advisory committee has recommended use of Captopril for patients with early signs of kidney damage. Although the study involved only type I diabetics, researchers suggest the results may be applicable to type II diabetics as well.

Traditionally, the diabetic facing end stage renal disease has had only compensatory treatments (dialysis and transplantation) in his or her arsenal. With Captopril, which cut in half the rate of kidney failure in its test population, there may now be real possibility for prevention.

Peter Nebergall reports new FDA-approved use for common high blood pressure medication.

My transformation (Continued from page 1)

done by a totally blind person. I also enjoy swimming, hiking, sailing, ice-skating, arts and crafts, cooking, baking, and writing poetry. Included here is one of my poems, "Natural High," expressing my outlook on life.

In closing, I would just like to say: "Never give up, and don't let anything get you down."

If anyone would like to write or call me, my address and phone number are: Betty Walker, 1826 Mississippi, Jefferson City, MO 65101; telephone: (314) 634-7969.

Natural High

Whenever I am feeling high,
I find it very hard to lie.
My face will have a big bright smile,
And when I talk, I talk a while.
My high is not from any drug;
I may be "up" from just a hug.
Its cause is just a love of life
That I hold on to with great strife.

Author's Postscript

My original article was written in February 1980, for the "Danbury Hospital Dialysis Newsletter," to encourage dialysis patients to choose transplantation.

I have now had my kidney transplant for fifteen and one-half years. I have had no major problems in those years, and my blood chemistries continue right in the middle of the normal range. I continue to do all of the things that I enjoy, and I work actively in the National Federation of the Blind.

David Walker, of Michigan, and I were married in 1982 in Minneapolis, Minnesota at the National Federation of the Blind Convention. Shortly after our marriage, a new job for Dave brought us to Jefferson City, Missouri, where we reside today.

I have been president of my local chapter of the National Federation of the Blind, and have served on the national board of our NFB Diabetics Division. I encourage anyone who is undecided about transplantation to "go for it."

Why all of us are Federationists

by Homer Page

Homer Page tells what it means to belong to the National Federation of the Blind.

Homer Page is the President of the National Federation of the Blind of Colorado and Chairman of the Boulder County Board of Commissioners. He is also a thoughtful and deeply committed Federationist. The following article is reprinted from the Winter, 1993, edition of The Voice of the Rocky Mountain Blind, *the publication of the National Federation of the Blind of Colorado. Here it is:*

Recently I attended a conference held by the Maryland Association of Counties. I had been asked to speak about the implementation of the Americans with Disabilities Act. After the day's activities, a group was sitting around discussing disability issues. I was asked about the National Federation of the Blind. The question that was posed to me was, "What does it mean to belong to the Federation?"

My interrogator really wanted to know what difference it makes in one's life to belong to the NFB. I have thought more about these questions, and here are some of my responses.

Federationists have a wide variety of characteristics. Some of us are totally blind, and some of us have normal vision. Most of us are somewhere in-between. We have widely differing political views, educational experiences, and abilities. Some of us are athletic, others have musical ability, and still others have neither. Some of us have very good travel skills, and others don't. Some of us are old, and some of us are young, and most of us are in-between. Yet, in spite of all these differences, there is something that binds us together.

I believe that this is the belief that blind persons are capable of living normal, fulfilling lives. In many ways society, through its ignorance and occasionally through its hostility, tries to prevent us from living the lives that we know are possible for us. We know that, if we work together to create opportunities and to support one another, our chances to fulfill our lives will be greatly increased.

We are proud of our organization, and we are proud of being members of the Federation. This pride comes from the continuing experience we have of our success in improving the lives of blind persons. Whether we are fighting discrimination, working with legislators, or taking on the media, we know that our work is of high quality. We also know that, if we need help or if we just need someone to talk with, the members of the Federation are there for us. This knowledge sustains us even if we never actually feel the need to consult with our friends.

You don't have to be a star to be loved and appreciated in the Federation. You don't have to be a great Braille reader or a super traveler to gain the respect of other members. The Federation works to improve training opportunities for its members, but we are not an elite organization. The Federation is for every blind and sighted person who believes that blind people can really play in the mainstream of life if they have the opportunity. We do not blame blind persons for failures that are not of their making. We do not believe that, if something goes wrong in a blind person's life, it is without a doubt the result of some fault in the blind person's character or ability. We believe that, when a blind person gets an equal chance, he or she will make the most of it.

Sometimes you just have to decide whose side you're on. The Federation is on the side of blind folks. We all know that. That's why we give all that we can to make the Federation a successful organization. Think of what we get in return.

The National Federation of the Blind

The National Federation of the Blind is the largest membership organization of blind people in the nation, having chapters in every state and approximately 50,000 individual members. It is the blind speaking for themselves. The National Federation of the Blind seeks to integrate the blind into society so that they are seen as normal, participating citizens—as people you would want to know, to hire, to work with, associate with in clubs and recreation.

We seek to show the public that we are just normal people who cannot see—not helpless and dependent, not blessed with special powers and gifts. We help the newly blinded learn that life can still be good. We show blind children that they can have a meaningful future. With proper training and skills, the blind can take a normal part in society—education, a job, a home, a family, normal recreation (camping, bowling, water skiing), and participation in community affairs.

We help blind persons find jobs—and the confidence to get and keep those jobs. Many willing, capable blind people have never had a job. Seventy percent of the blind are unemployed. Many of the rest are underemployed.

Our work is in the best interest of every American—our work to reduce blindness from a tragedy to a mere nuisance, our work to help the public accept the blind as normal people, our work to see that blindness does not mean isolation and dreadful loneliness.

How Can I Help?

You can inform yourself about blindness and help inform others. You can write for our literature, and you can get to know blind persons in your community. Blindness can happen to you or to one of your friends or to a member of your family. Don't wait for it to happen before doing something about it. You can begin today.

You can also help by making cash contributions to our organization or remembering the National Federation of the Blind in your will. The National Federation of the Blind is supported by public contributions. Donations are tax deductible and may be sent to: Treasurer, National Federation of the Blind, 1800 Johnson Street, Baltimore, MD 21230.

Erythropoietin used more after government reimbursement reformed

Johns Hopkins researchers have found that some doctors underprescribed a medication based on financial rather than medical considerations. However, when Congress reformed Medicare's reimbursement policy, many of those same doctors dramatically changed their prescribing practices.

In studying the use of a genetically engineered drug, Hopkins researchers found that the initial doses were lowest, and post-reform changes greatest, at for-profit centers. Still, not-for-profit facilities also used more of the drug when a better reimbursement policy became available.

"Our study shows how insurance payment policies can influence the practice of medicine," says Neil Powe, M.D., M.P.H., lead author of a study that appears in the October issue of *American Journal of Kidney Diseases*. "In addition, it illustrates how the same policies impact different types of health-care institutions," says Powe. "Health-care reform leaders need to recognize the importance of alternative payment policies and we should closely monitor care given to Medicare and other patients."

In 1989, the Food and Drug Administration approved the use of recombinant human erythropoietin (rHuEPO) after it was found to stimulate red blood cell production, leading to a better quality of life for many anemic kidney dialysis patients. Higher doses of the drug produce a better response.

Initially, Medicare reimbursed 80 percent of an allowed $40 charge for a rHuEPO treatment of up to 10,000 units, says Powe. A typical dose for a dialysis patient averaged 4,000 units, three times a week, at a yearly cost of about $5,000. The patient or a co-insurer paid the remaining 20 percent.

But health officials noticed that prescribed doses of the drug were lower than those recommended by earlier clinical trials. Concerns were raised that providers were responding to financial incentives, so Medicare changed its reimbursement plan in January 1991.

The new plan allowed dialysis centers to charge $11 for each 1,000 units used. So instead of reimbursing for the drug "per treatment," they were reimbursing according to units used. Under the former policy, lower dosing of the drug could be linked with cost savings.

"We found that dosing was, on average, 14 percent greater," says Powe, who studied more than 70,000 patients with end stage renal disease. All were on dialysis. "More of the drug was being used at a lesser cost to the government immediately after the change in policy."

In for-profit freestanding centers, researchers recorded a 25 percent dosage increase over the first six months after the reform; a 27 percent increase in for-profit hospital centers; a 12 percent increase at not-for-profit freestanding centers; and a 12-percent increase at not-for-profit hospitals. The smallest change occurred at government facilities, which increased use by three percent.

Co-researchers in the study were Robert Griffiths, Sc.D.; Gerard Anderson, Ph.D.; Greg de Lissovoy, Ph.D.; Alan Watson, M.D.; Robert Herbert and Paul Whelton, M.D., of Hopkins. Joel Greer of the Health Care Financing Administration (HCFA) of the U.S. Department of Health and Human Services was also an author.

This research was funded by a grant from Health Care Financing Administration.

Independent, home, self-care dialysis possible for blind persons with kidney failure

by Lois M. Schmidt, R.N., C.N.N.

Lois Schmidt, R.N., C.N.N., is a certified nephrology nurse formerly with the Peritoneal Dialysis Unit at Dialysis Clinics, Inc., Columbia, Missouri. She now holds a similar post at Baptist Hospital, Nashville, Tennessee.

Kidney failure is a disease occurring in about half of those people who have diabetes. It presents new challenges to the person who may at the same time be experiencing visual changes or blindness.

Preparation for dealing with kidney failure should include a thorough education program to adequately assess all the choices for treatment. Some patients who are eligible will seek a kidney transplant to replace their failing kidney function. Others will decide to use a dialysis therapy. Those who choose transplant usually also require a period of dialysis treatment prior to transplantation.

There are two basic types of dialysis therapies, with many variations depending on the provider dialysis unit. Hemodialysis is usually done at a dialysis clinic by specially trained nursing staff. However, it may be done at home if the patient has a partner who can be taught to perform the treatment. Peritoneal dialysis, commonly called CAPD (continuous ambulatory peritoneal dialysis), is a self-care, home therapy.

Peritoneal dialysis works inside the body. It utilizes the peritoneal membrane, which forms a "sac" inside the abdominal cavity, to remove waste products and extra fluid from the body. This process is accomplished by allowing dialysis solution to flow into the peritoneal cavity by way of a permanent tubing called a catheter which is surgically placed through the abdominal wall. The solution remains in the abdomen for four to eight hours while the person goes about his or her usual activities. At the end of this time, the dialysis solution is drained out and is exchanged for fresh dialysis solution. This "exchange" is usually performed four times daily. Special training is provided to patients choosing CAPD to enable them to successfully use this therapy. All patients (including those without visual problems) are encouraged to have a family member or friend participate in their education sessions. Most people find it very reassuring to have a support person available if needed.

The exchange procedure of CAPD can be performed by a blind person using one of several assist devices available on the market today. This specialized equipment, as with all home dialysis supplies, can be obtained through dialysis units. For economic reasons some dialysis clinics make use of supplies from only one company and thus offer only one type of device. However, there are at least four different types of systems available which may be used by a patient with visual impairment and/or neuropathy (nerve damage) of the hands. Some of the devices feature an ultraviolet light which provides extra protection against infection. Others make use of large or recessed connections to help prevent contamination. Each system has some special features which may make it preferable for an individual patient's needs.

Another form of peritoneal dialysis is CCPD (continuous cycling peritoneal dialysis). This type of dialysis makes use of an automated cycler which is designed to operate while a person is asleep. The cycler is programmed to exchange the dialysis fluid at periodic intervals during the night. While this dialysis is more complicated than CAPD, it does allow daytime freedom from exchanges. Also, it may be the appropriate choice for a patient who requires the assistance of another person.

As with all things in life, peritoneal dialysis is not without its disadvantages. The most serious complication of this form of dialysis is infection of the peritoneal cavity. This infection can usually be treated successfully with antibiotics. However, great care must be taken by the patient to pay attention to cleanliness and meticulous details to avoid infections if at all possible.

There are also advantages of CAPD. One, particularly beneficial for the diabetic, is that insulin may be added to the dialysis solution rather than being given as an injection. Insulin administered in this way is absorbed and used by the body in a way that usually results in good blood sugar control. CAPD is a slow, continuous, gentle form of dialysis which provides a steady chemical and fluid balance in the body. This can aid in maintaining normal blood pressure as well as providing a sense of well-being. Since CAPD is performed at home, the necessity of travel to a dialysis center three times a week is eliminated.

CAPD has proven to be an effective form of dialysis for persons with diabetes, including those with visual impairment and neuropathies. Extensive education is required prior to the decision for choice of dialysis therapy. Each individual must make his or her own decision based on careful evaluation of needs, motivation and family support, as well as emotional and physical capabilities. Those persons most successful with CAPD are those who are highly motivated to participate in their own health care.

(From the Editor: I have received reports that sometimes, when blind diabetics begin dialysis treatments, they aren't told about CAPD. Because of the diabetic's blindness, his/her physician doesn't always explain the different types of dialysis treatments. Unfortunately, it is, in some cases, assumed that because the patient is blind, he/she won't be able to use CAPD therapy.

I visited Lois Schmidt, R.N., C.N.N., at Dialysis Clinics, Inc. (DCI) Peritoneal Dialysis Training Room in Columbia, Missouri. She showed and explained to me step by step what CAPD patients, blind and sighted, must do to successfully use this form of treatment. The training room contained a dummy doll with a CAPD catheter connected to its lower abdomen. I actually went through the process of hooking and unhooking the dialysis bags with and without solution for the CAPD exchange.

All CAPD patients must be careful not to touch and contaminate the ends of the catheter tubing, which could cause infection to the peritoneal cavity. Blind patients are trained how to use the ultraviolet germicidal exchange device. This instrument delivers a dose of ultraviolet light, which kills almost all bacteria on key components of the catheter and exchange system connections. Some dialysis units require that all patients, blind and sighted, use some sort of exchange device when connecting and disconnecting solution bags. Lois Schmidt said that, "When blind or visually impaired people become familiar with the system, and can do it well and efficiently, they're no more at risk than anyone else." She also said that when diabetes has advanced to the point where the patient has lost his/her sight, they often, from neuropathy, lose the feeling in their fingertips as well. It is imperative that blind patients have fairly good sensory ability in their fingers because they must be able to feel slots and/or openings to correctly use the ultraviolet

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Blood chemistry values for dialysis patients

by Patricia Hansen, RN

Patricia Hansen, RN, is the Director of Dialysis Services at the Chronic Dialysis Center, Good Samaritan Hospital of Long Island.

BLOOD CHEMISTRY VALUES

BLOOD CHEMISTRY	NORMAL VALUES	ACCEPTED NORMALS FOR DIALYSIS PATIENTS	CAUSES OF ABNORMALS (I.E. OF HIGH ABNORMALS UNLESS OTHERWISE NOTED)	SIGNS AND SYMPTOMS ASSOCIATED WITH ABNORMAL LEVELS
Calcium (Ca)	8.5 - 10.5	Same	**Low calcium** - eating too many phosphorous foods. Not taking phosphate binders. Will go down if phosphorous goes up.	**Low calcium** - muscle twitching and cramping, seizures, varying degrees of depression, hair loss, cataracts and conjunctivitis.
			High calcium - medications such as Rocaltrol or Calderol may cause sharp increase if blood not checked regularly.	**High calcium** - muscle weakness, fatigue, constipation and abdominal cramps, nausea, vomiting, loss of appetite. If prolonged, calcification of blood vessels, including coronary arteries.
Phosphorous (PO4)	2.5 - 5.0	Same	Not taking phosphate binders. Eating too many foods with phosphorous, e.g., milk, cheese, organ meats, beans.	Calcium deposits in blood vessels, leading to heart and eye problems. Breaking of bones without specific injury (spontaneous), continuous bone pain — especially hips, knees, and ankles. Causes elevated parathyroid hormone.
Magnesium (Mg)	1.7 - 2.3	Same	Elevations due to taking phosphate binders containing magnesium or other medications, such as Milk of Magnesia or Citrate Magnesia.	Decreased mental function ranging from drowsiness to insevere state coma. Decreased tendon reflex leading to paralysis. Nausea and vomiting. Hypotension due to dilation of blood vessels.
Hematocrit (Hct)	36 - 52	Will be lower — varies with patient. (Average is mid-20's)	Decreased production of red blood cells. Blood loss during or after dialysis.	Fatigue, shortness of breath, chest pain on exertion.
Glucose	80 - 120	Same	Diabetes. Recently eating very sweet foods.	Excessive thirst.
BUN	10 - 26	Less than 100.	Eating too much protein food.	Fatigue, nausea, insomnia, dry and itching skin. Taste and smell affected, urine-like body odor and breath.
CO2 Bicarb	21 - 30	Not less than 12.	Eating too much protein food, creating a more acid blood — lowering CO2.	Slow, shallow breathing.
Sodium (Na)	133 - 150	Same	Eating too much salt, e.g., bacon, potato chips, canned vegetables.	Edema, elevated blood pressure, shortness of breath, elevated weight, sticky mucous membranes, elevated temperature, flushed skin color, rapid heartbeat.
Chloride (Cl)	95 - 108	Same	Same as Na.	Same as Na.
Creatinine	Below .25	12-28 Varies with muscle mass. Should not change more than 2.0 gain. Should remain about the same.	Inadequate dialysis time. Breakdown of muscles (often given off by muscle after exercise).	

BLOOD CHEMISTRY	NORMAL VALUES	ACCEPTED NORMALS FOR DIALYSIS PATIENTS	CAUSES OF ABNORMALS (I.E. OF HIGH ABNORMALS UNLESS OTHERWISE NOTED)	SIGNS AND SYMPTOMS ASSOCIATED WITH ABNORMAL LEVELS
Potassium (K)	3.5 - 5.4	Same	Eating too many foods with potassium, e.g., green leafy vegetables, fruit, meat, coffee, and nuts.	Heart stops, vague symptoms — occasional weakness, numbness, irregular heartbeat.
Enzymes				
SGOT	10 - 50	Same	Hepatitis Pancreatitis Pericarditis	Nausea, vomiting, abdominal cramping, fatigue. Nausea, severe abdominal pain. Chest pain on inspiration.
GGT	7 - 33	Same	Hepatitis Pancreatitis	
Alkaline Phosphatase	30 - 115	Same	Not taking phosphate binders.	Painful joints. Weakened bones, which could lead to severe pain and/or deterioration requiring surgery.
Parathyroid Hormone (PTH)	Intact 163 - 347 C-Terminal	Same	Long-term imbalances of calcium and phosphorus.	Same as elevated phosphorus.

Renal failure, dialysis, and transplantation

(Continued from page 8)

contact their dialysis social worker or transplant coordinator.

- ***Is there any assistance available to help with the cost of immunosuppressive medications?*** The Transplant Foundation, 8002 Discovery Drive, Suite 310, Richmond, VA 23229; telephone: (804) 285-5115, is a national, nonprofit, volunteer organization providing grants to transplant recipients to offset the costs of immunosuppressive medications.

- ***Where can someone go who wants to find out more about dialysis and transplant options?*** Talk to your physician, contact local dialysis clinics, or any of the 219 transplant centers in the United States.

• • •

Sources:

1. HCFA, 1993 (Publication HCFA #03337) "The National Listing of Medicare Providers Furnishing Kidney Dialysis and Transplant Services"

2. US Renal Data System, USRDS, 1993 Annual Data Report, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, Feb. 1993

3. Lois Schmidt, R.N., C.N.N., is a certified nephrology nurse who worked with the Peritoneal Dialysis Unit at Dialysis Clinics, Inc., of Columbia, Missouri. She is presently holding a similar post at Baptist Hospital, Nashville, Tennessee.

4. The United Network For Organ Sharing (UNOS)
1100 Boulders Park, Suite 500
Richmond, VA 23225; telephone: (804) 330-8500

5. University of Minnesota Hospital has the largest transplant center in the world. Pioneers in transplantation, they have carried out more than 4000 kidney transplants, as well as the first human pancreas transplant. The center has an information packet, which it will send to anyone interested in kidney transplantation. The center has prepared a comprehensive text for patients, explaining kidney transplantation before, during and after, and this text is also available on audiocassette for the blind. For further information, contact the University of Minnesota Hospital Transplant Center; telephone: 1-800-328-5465.

I know Minnesota best because I had my transplant there, more than ten years ago. There are many fine transplant centers in the U.S.; check them out! The Diabetics Division of the National Federation of the Blind has the "Renal Failure: Dialysis and Transplantation" committee, formed to serve diabetics who are experiencing renal failure. For information about this committee, and our many others, contact ***Voice of the Diabetic.***

If you or a friend would like to remember The Diabetics Division of the National Federation of the Blind in your will, you can do so by employing the following language:

"I give, devise, and bequeath unto The Diabetics Division of the National Federation of the Blind, 1800 Johnson Street, Baltimore, Maryland 21230, a District of Columbia nonprofit corporation, the sum of $_____" (or "_____ percent of my net estate" or "the following stocks and bonds: _____") to be used for its worthy purposes on behalf of blind persons."

Independent, home, self-care dialysis

(Continued from page 11)

germicidal exchange device. DCI provides several days of step by step training for CAPD patients.

Lois Schmidt said that some blind diabetics may have difficulty adding medication, such as insulin, to the bag if there is a problem with dexterity. The insulin syringe needle is inserted into a small port, which must be prepped with an anti-bacterial solution. There is a needle guide available that enables blind persons to independently do this, but it is imperative that neither the port nor the guide be contaminated. It doesn't take much bacteria introduced into the port area to cause infection. The peritoneal cavity is a sterile area. This cavity contains no white blood cells to fight infection. As soon as bacteria is introduced, it colonizes, multiplies, and very quickly infects the cavity.

I am a blind diabetic who had no trouble with the CAPD exchange procedure. It is important to realize that some dialysis patients, whether they are blind or sighted, can use CAPD, and some cannot. It is well documented that there are alternative techniques which enable blind citizens to participate fully in mainstream society.)

Board Members

The Diabetics Division of the National Federation of the Blind.

Ed Bryant, President, 811 Cherry Street, Suite 309, Columbia, MO 65201; Phone: (314) 875-8911

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Tom Ley, Secretary, 2514 Deas St., Bossier City, LA 71111; Phone: (318) 746-0356

A donor's story

by Debbie Dupree

Debbie Dupree, pictured with husband Steve and children Larry, Chrissy, Daniela, and Jesse, shares her experiences as a kidney donor. Daniela and Jesse were born after she donated a kidney.

After three years on dialysis, my brother Ed needed a kidney; *everybody* in the family volunteered to donate. Our entire family sent the required blood samples to the University of Minnesota for testing, where the operation would take place if one of us proved to be a compatible donor. Our parents were ruled out because of age so it was narrowed down to Jim, my second brother, or myself.

Ed's doctor called me at my office to tell me I had been chosen. My blood tissue was a good match with Ed's and if I were willing to be the donor, he would not have to undergo the removal of his spleen prior to the transplantation. (*Editor's Note:* Splenectomies are no longer needed for transplantation.) I told Ed's doctor that he could count on me.

A battery of tests was needed to determine my good health and the compatibility of our kidneys. Our kidneys turned out to be a perfect "four antigen" match! The University of Missouri Hospital did the pretesting. They were very cooperative, working with and around my own work schedule. Since my sick leave was limited, I had the testing done as an outpatient.

I was fortunate that my work was within walking distance from the clinic, and that my supervisor was extremely understanding and cooperative. I'd like to say here how much I appreciate the thoughtfulness and consideration my employers showed me at that time. I worked with the Missouri Department of Mental Health, and everyone was concerned about me and worked with me to make the organ transplant possible. They helped me obtain the necessary leave time and were very supportive.

The tests, neither complicated nor painful, consisted mostly of bloodwork, urine tests, and a few x-rays. I spent about 12 to 16 hours as an outpatient. My husband's employers, considerate and understanding, allowed him to take as much time off as was necessary.

In May 1983, the time finally came for us to make the 500-mile trip to Minnesota. We were impressed when we got there. Minneapolis and St. Paul are beautiful cities and the University Hospital is huge, but the staff was warm and friendly. They did everything they could to make us comfortable.

All of my test results had been sent to Minneapolis, but there was one more test needed — the angiogram to determine which of my kidneys they would use. I must say this was the most painful test of them all. But, praise the Lord, it didn't last long.

Then it was discovered that Ed's white blood count was too low for surgery, and I was released from the hospital. We all returned home to wait. It seemed like a long wait because I had been ready and anxious to get the transplant over. It must have seemed even longer for my brother.

Three months later, in August, we were ready to go again. This time my son, who was ten years old at the time, was out of school and went with us. My daughter, seven, stayed with her granddad while we were gone.

We were admitted into the University of Minnesota Transplant Center and the routine preparation was done. I felt very relieved that everything was ready and that the next morning would be the big day. It's difficult to express how I felt the night before surgery. I don't like being in hospitals, and the idea of being cut on didn't thrill me. I thought of my brother — it would be harder for him because he was not healthy. I had concerns about the success of the transplant, and I worried about how my brother would feel if the kidney didn't "take." But, success or failure, Ed deserved the chance. I had faith that God was with us in this, and that He was in control. My family, friends, and many church congregations had been praying and continued to pray for the complete success of the transplant and for God's peace to be with us. That night I felt the peace of God and was ready for the next day.

We were in surgery for four to five hours. I don't remember much of that first day except waking now and then and seeing that my family was there. As I gained consciousness, I felt the pain from the incision and the muscles around it. I discovered muscles I had never been aware of before. It was agony to move and especially to cough or sneeze.

The doctor told me I'd be in the hospital seven to ten days after the surgery, but I recovered quickly and was released after only four days.

The drive home from Minnesota stands out in my memory as one of the roughest parts of the entire ordeal. I had four pillows surrounding me in the car to help cushion me from the bumps and jolts, but it was an exhausting trip to say the least.

I felt like an invalid for the first week at home. I couldn't lift over ten pounds, I could barely get out of a chair by myself, and I couldn't get out of bed by myself. Our waterbed created quite a problem. Since there is nothing solid on a waterbed to push or pull on, I found myself marooned in bed more than once. One time I was stuck in bed half a day until someone came home to rescue me!

Gradually, faster than I had expected, I was able to get around and do for myself. I could have gone back to work four weeks after the transplant but didn't until after six weeks, at which time the only physical evidence of the transplant was a numbness around the incision site. Now, after ten years, I'm feeling just fine. I just never think about it.

If you are in need of a kidney and there is a possibility to receive one from a living related donor, don't be afraid to ask. If you are related to someone in need of a kidney and you have two healthy ones of your own, don't be afraid to offer this gift of life. It is not traumatic. The time and discomfort involved are minimal compared to the physical and spiritual lift experienced by donor and recipient.

I honestly do not miss the kidney I gave away. Neither my life nor my health has been changed, but my brother's has. Because of a kidney that I didn't need and don't miss, he is a productive person again.

Postscript from Ed Bryant:

I have felt great ever since having a kidney transplant. I would be remiss if I did not use this opportunity to say I will be eternally grateful to my sister. I simply want to convey the feeling of love I have for her. I strongly recommend all people with renal failure to consider a kidney transplant. The National Kidney Foundation is correct when they say the kidney is the "Gift of Life."

As Debbie has already stated, neither her life nor her health has changed since her generous gift to me, except that on March 3, 1986, she gave birth to Daniela Ann Dupree, a beautiful, healthy baby, 20 inches long and weighing in at 6 lbs., 14 ozs.; and on October 10, 1989, to Jesse Arron Dupree, 19½ inches long, 7 lbs., 5 ozs.

Transplant patients speak

What's it like? These people are all diabetics, and all are living with kidneys they received more than ten years ago. See for yourself!

• Linda Bingham, of Cincinnati, Ohio, received a dual transplant (kidney and pancreas) at University Hospital in Cincinnati on December 10, 1981, **more than twelve years ago**. She says, "I feel great. I have been given a whole new life."

• Ed Bryant, of Columbia, Missouri, received his kidney transplant at University of Minnesota Hospital in Minneapolis on August 9, 1983, **more than ten years ago**. He states, "Because of my new kidney, I feel energetic, and my quality of life is far better."

• Ken Carstens, of Virginia, Minnesota, received his kidney transplant at University of Minnesota Hospital in Minneapolis on September 10, 1975, **more than eighteen years ago**. In his words, "It's been eighteen years now, and I'd make the same choice again."

• Christina Cequiel, of Buenos Aires, Argentina, received her last transplant (kidney and pancreas) at University Hospital in Cincinnati on August 9, 1982, **more than eleven years ago**. She states, "My transplants are the gift of life. I thank the Lord."

• Eivind Frost, of Great Falls, Montana, received a cadaver kidney at University of Minnesota Hospital in Minneapolis on April 24, 1973, **almost twenty-one years ago**, and is doing fine. He tells us, "I've been feeling great for twenty years now."

• Karen Mayry, of Rapid City, South Dakota, received her kidney transplant at University of Minnesota Hospital in Minneapolis on January 12, 1977, **almost seventeen years ago**. She declares, "I feel great!"

• John Redlin, of Fort Pierre, South Dakota, also received his transplant at University of Minnesota Hospital in Minneapolis on January 12, 1977, **almost seventeen years ago**. Same day, same place. He tells us, "I have had a great seventeen years with my transplant."

• Betty Walker received her transplant at Yale-New Haven Hospital in Connecticut on July 13, 1978, **more than fifteen years ago**. In her words: "I was just existing on dialysis; and my transplant gave life back to me."

These folks know what they're talking about. Collectively, they have more than **122 years** experience living with kidney transplants! All of them would choose a transplant again. Although kidney transplantation is not for everyone, it should be given strong consideration. These people did!

My kidney transplant

by Ed Bryant

Ed Bryant explains his kidney transplant. He says, "go for it."

My cross to bear in life is diabetes. I found out how insidious the disease can be in 1978, when my physician told me I was undergoing renal failure, and that soon, when my kidneys could no longer filter waste from my system, I would have to go on dialysis.

I began dialysing in December of 1979. My treatments were three times a week and each lasted about four hours. I continued this regimen for the next 3½ years. I was a lucky diabetic at first. I usually felt great after dialysing, and unlike many, could continue my normal daily activities. I traveled quite a bit during this period, and dialysed at centers in other communities. I found that many dialysis patients feel nauseated and weak after treatments, requiring the remainder of the day to regain their strength.

After about three years on dialysis, my luck started to run out; I began to feel ill. I lost weight and had a constant pale look. I was not doing well at all.

When I attended the 1982 convention of the National Federation of the Blind, I heard a presentation by Dr. John Najarian, Chief of Surgery at the University of Minnesota Hospital in Minneapolis. He covered the topic of kidney transplantation in diabetic patients. After hearing Dr. Najarian's speech, I knew I needed more information on kidney transplants before I could consider one as an alternative to the dialysis treatments that were causing my health to fail.

My research supported the viability of transplantation. I found that the life expectancy of kidney transplant recipients is significantly longer than that of dialysis patients. And although some individuals might not qualify for a transplant because of other physical factors, I was lucky — the doctor considered me an ideal subject. I weighed the evidence, considered the odds, and decided to "go for it."

For a number of reasons, I chose the University of Minnesota Hospital for my transplant surgery. Although there are approximately 230 transplant centers in the United States, the University of Minnesota pioneered transplantation for diabetic kidney patients. To date, they have performed more than 4,000 kidney transplants, and they do an average of 200 per year. Their success rate is higher than the national average.

The transplant center offers an information packet, explaining kidney transplants, to interested consumers who call them toll-free at 1-800-328-5465. Upon entering the hospital, patients are provided a manual explaining transplantation before, during, and after surgery. Blind patients may receive this manual on audiocassette.

My sister, Debbie, was to donate one of her kidneys to me. I will be eternally grateful for this generous act of love. It is a wonderful gift and my feelings for this act are indescribable.

My first step was to start taking the immunosuppressive drug Imuran, which would protect my new kidney against my body's efforts to reject it. But something went wrong and on the day I checked into the hospital to prepare for the transplant, the doctors found that the drug had caused my white blood cell count to fall to a dangerously low level. The surgery was postponed until my body could replenish its white blood cells. The Imuran was stopped, and I went back home.

While waiting for my white blood cell count to rise, I learned about a new immunosuppressive drug called cyclosporine. The Food and Drug Administration had not yet officially approved cyclosporine, but it was being tested at various transplant centers, and the results to that point had been extremely positive. The kidney survival (non-rejection) rate greatly exceeded that of any other drug of its type.

Two months later, in August of 1983, my white blood cell count finally returned to a normal level. When I returned to the transplant center, I asked the doctors if I could be a "guinea pig" in the cyclosporine tests. The surgeons told me I could, and that they foresaw no problems with the revolutionary new drug.

A new kidney, like mine, is placed in the lower abdomen, where it is best protected. Kidney recipients receive only one kidney, which is all that is needed to handle bodily functions. A newly transplanted kidney will grow or diminish in size as needed to best serve the body in which it is placed.

I received my new kidney on August 9, 1983. My surgery went very well. I was amazed and pleased at how quickly I recovered and how minimal the discomforts and complications were. Because I experienced no rejection episodes, I was able to leave the hospital after only eight days. Some recipients have "rejection episodes," and although they probably won't lose the kidney, they take longer to stabilize and heal. I was lucky.

Like all other transplant recipients, I was placed on immunosuppressive therapy, which I will continue for life. My first prescriptions were cyclosporine and prednisone. Several months later, the hospital began "triple therapy," yet another University of Minnesota innovation, which is a mixed-dose regimen of cyclosporine, prednisone, and Imuran. I continue this same triple therapy today.

My transplant made a tremendous difference in my quality of life. Almost immediately I felt more energetic, no longer tired and drained as I was on dialysis. My spirits were high, my mental processes sharp, and I was ready and able to handle a busy schedule. Today, more than ten years later, my transplanted kidney is doing fine and I remain as active as ever.

I strongly endorse kidney transplantation. I am a living example of the improved quality of life after a transplant. I say "go for it!" Check out the possibilities and get answers to all your questions before you make a decision. Ask different doctors. Talk to someone who's had a transplant. Consult a transplant center or a transplant surgeon. Your nephrologist should be able to help. Your quality of life, and in fact your life may hang in the balance.

I hope my experiences will provide you with food for thought. If you have any questions, please feel free to contact me.

Ask the Doctor

by Wes Wilson, M.D.

NOTE: If you have any questions for "*Ask the Doctor*," please send them to the *Voice* editorial office. The only questions Dr. Wilson will be able to answer are the ones used in this column.

Wes Wilson, M.D. is an Internal Medicine practitioner at the Western Montana Clinic in Missoula, Montana. Dr. Wilson was diagnosed with Type I diabetes in 1956 during his second year of medical school.

Q: I've lived with diabetes 15 years and feel my control is good. For almost a year I've noticed tingling and, at times, burning of my feet. It seems especially troublesome at night. Is this related to diabetes? What can I do to get relief?

A: A physician must be careful not to jump to conclusions, but your symptoms certainly suggest that your complaints are related to diabetic neuropathy. Even though your history and symptoms suggest this is related to diabetes, it is important to point out that other conditions can cause the trouble you describe. I believe you do have problems with nerve conduction, especially of the nerves that function to carry sensory impulses. Lack of vitamin B12, lead poisoning, and other metabolic diseases can all cause similar problems. It is the doctor's job to decide which is the correct diagnosis through history, examination and appropriate tests.

We will assume you have diabetic neuropathy — which is certainly the most likely diagnosis.

Blood sugars higher than normal can cause abnormality of nerve function after years, at least partly from accumulation of sorbitol or other sugars in the nerve fibers where these sugars interfere with nerve function and eventually can cause nerve cell injury and death. Sensory nerve fibers carry sensation and are often affected early and are noticeable by the affected person when they are not functioning normally. The symptoms include lack of sensation, numbness, tingling, burning and coldness. The longest nerves are usually affected first so that the tingling and burning are often first noticed in the toes — those are the longest nerves in the body. Like most complications of diabetes, this may be progressive and may also affect other nerves. When the autonomic nerves are affected, there can be problems with stomach emptying, bladder emptying, and a tendency to low blood pressure upon standing.

Like other complications of diabetes, diabetic neuropathy is to be prevented if at all possible. Proof that very tight control of blood sugar can prevent nerve injury has been weak, but since the June 1993 report of the Diabetes Control and Complications Trial, we now have good evidence that nerve injury can be prevented or delayed in persons who tightly control their blood sugars as compared with a group of persons with less meticulous control.

A group of drugs called aldolase reductase can also prevent the deposition of sorbitol in the nerve fibers and prevent progressive nerve injury in diabetics — if they are started early enough. None of these are available as yet, but they promise the hope, at least, that they can prevent nerve injury in diabetics.

If symptomatic nerve injury has occurred, relief can often be obtained with amitriptyline or some related drugs. These do not improve nerve function but often give good relief of the symptoms. Some very resistant cases can obtain relief with application of cream that contains extract of hot pepper plants. Administration of vitamin B12 when it is **not** deficient does not work.

Above all else, do the best you can to *prevent* the complications by carefully controlling diabetes. It is worth the effort.

Ann Terry is a registered dietitian who works at the State Hospital in Fulton, Missouri and at the Veterans Administration Hospital of Columbia, Missouri. She graciously calculates the diabetic exchanges and food values for our recipes.

Send your great ideas to the editor. He is the official taste tester and needs recipes to test his taster.

Quick Bread

from Harlan A. Prentice
of Columbia, Mo.

3 cups all-purpose flour
2 rounded tbsp. granulated sugar
1 rounded tsp. baking powder
small pinch of salt
Mix thoroughly.
Add wet ingredients:
2/3 cup skim milk
Egg Beaters (enough to equal 1 egg) or 1 med. real egg
2 heaping tbsp. diet margarine
slightly less than 1/4 cup water

Mix dough by kneading with hands. If dough gets stiff, run hands under tap water and go back to mixing with hands still wet. Dough should look like stiff cookie dough and it smells like play-dough. If the dough is still too stiff, keep adding water with your hands. Bake about 30 min. at 375 degrees in a small-loaf bread pan greased with any non-stick pan coating. With slightly buttered hands, pat top of loaf before baking. It will look like a split loaf and have the texture of light pound cake.

Yield: 16 servings (1 slice per serving); Calories: 100; Diabetic Exchanges: 1¼ bread.

Rhubarb Bake

from Karen Mayry
of Rapid City, S. Dak.

4 cups rhubarb
2 tbs. orange juice
1 cup sugar equivalent (Sweet and Low, Sweet One, etc.)
Rind from 1 orange — grated

Mix all ingredients. Bake at 350 degrees for 40 minutes. Yield: 8 servings; Calories: 25; Diabetic Exchanges: 1 vegetable.

Mostaccioli Chicken Casserole

from Frances Allen
of Columbia, Mo.

1/2 lb. mostaccioli macaroni
1 stewing chicken (4 lbs.) — no skin
3 tbs. margarine
5 lbs. flour
4 cups chicken broth
4 cups skim milk
1½ tsp. salt
1/2 tsp. celery salt
1/4 tsp. ground pepper

Stew chicken; reserve fat, broth, and meat. Melt chicken fat and margarine. Blend in flour. Add chicken and milk. Cook over low heat until thickened. Add seasoning and chicken meat. Add drained mostaccioli. Bake for 45 minutes at 350 degrees.

Yield: 10 servings; Calories: 380; Diabetic Exchanges: 3 meat, 2 starch.

Orange Lemonade

This recipe appeared in the Volume 1, Number 1, August 1993 issue of the *Equal Sweet News®*, reprinted with permission. Equal® Sweetener is a registered trademark of the Nutra-Sweet Company.

1 cup freshly squeezed lemon juice (4 to 5 lemons)
1 cup freshly squeezed orange juice (3 to 4 oranges)
12 packets Equal® or 3½ tsp. Equal® Measure™
3 cups water
Ice cubes
Lemon slices (optional)
Mint sprigs (optional)

In a large pitcher combine juices and Equal®; stir to dissolve. Stir in water. Cover and chill. Serve over ice. Garnish each serving with a lemon slice and mint sprig, if desired.

Yield: 5 (8-ounce) servings. Nutrition information per serving: 44 calories, 1 g. protein, 12 g. carbohydrate, 0 g. fat, 0 mg. cholesterol, 5 mg. sodium. Diabetic Exchanges: 1/2 fruit.

Medicare to pay for shoes for diabetics

by Neil M. Scheffler, M.D.

Dr. Scheffler, Chairman of the Patient Education Committee of the American Diabetes Association, Maryland affiliate, is a podiatrist in private practice in Baltimore, MD.

Diabetic patients are at risk for developing serious foot problems. As a podiatrist I see these problems lead to ulcerations, infections, gangrene and amputations. Medicare, in an attempt to decrease the number of these disasters, has authorized payment for therapeutic shoes for diabetics who meet certain criteria.

The "Therapeutic Shoe Bill" was passed by Congress after a four-year project to evaluate the cost-effectiveness of providing special shoes to diabetics at risk of complications. They believe that providing these patients protective footgear will save money in decreased medical costs. I agree completely. This is a giant leap forward in an attempt to prevent disease before it occurs rather than treat more severe problems later.

Diabetics often develop diabetic neuropathy, a disorder of the nerves of the feet that decreases sensation. Since the feet are numb, pain is not felt by these diabetics. A corn, bunion or callus which would cause pain due to shoe pressure in a person without neuropathy causes no pain in those with diabetes and neuropathy. The person continues to walk. The pressure or friction eventually causes a blister or ulcer in the area. Since diabetics may also have difficulty healing a wound, the ulcer may progress to infection and the severe problems I spoke of earlier.

Blood supply to injured tissue is vital for healing and to allow the body to combat infection. As we age, the circulation to our feet often decreases. This process may happen earlier in people with diabetes. Prevention of pressure and friction to the feet of diabetics with poor circulation is crucial. Your podiatrist or diabetes doctor can check your circulation for you.

Under the new Medicare plan certain diabetics will be supplied with shoes. These diabetics must be under a comprehensive care plan by the physician who cares for their diabetes. In addition, they must have either poor circulation, neuropathy, a callus that could become an open ulcer, a previous ulcer or a previous partial amputation. Many diabetics on Medicare meet these criteria.

The patients who qualify are entitled to one pair of either molded shoes or extra depth shoes a year. In addition they can receive up to three pair of special insoles for these shoes every year. These shoes and innersoles will protect the sensitive feet of these patients.

If you are a diabetic and have Medicare you should contact your podiatrist to arrange for an evaluation to see if you qualify under this program. These benefits can help keep you healthy and walking. Take advantage of them.

Letters to the editor

Alda Anderson
Oregon Diabetes Association
Roseburg, OR
November 3, 1993

Voice of the Diabetic
Columbia, MO

Dear Sir:

I would like to receive 25 copies per quarter of your wonderful and very informative paper, to our support group. We usually have from 30 to 35 in attendance each month. I am pleased to know it is available, especially for our support group.

We are an independent group and hope to help anyone in our region who needs diabetes education.

Keep up the good work as I find your publication invaluable and the articles very realistic.

Sincerely
Alda Anderson
Treasurer

• • •

John Getsy
Somerset County Office for the Disabled
Somerville, NJ
November 5, 1993

Ed Bryant, Editor
Voice of the Diabetic
Columbia, MO

Dear Mr. Bryant:

As usual, I once again was enlightened by the most recent issue of the ***Voice of the Diabetic.***

I currently lend my taped version of the ***Voice*** to all who are interested and would like to continue to spread the word. Would it be possible to receive at least five copies of the print version for use in my office? It would also be greatly appreciated if you could forward a quantity, two dozen or so, of the brochure "Diabetes, Complications, Options" as well.

I thank you in advance for your kind considerations and would like to commend you on a job well done. I hope it never ceases.

Sincerely,
John Getsy, Coordinator
Office for the Disabled

• • •

Andrew D. Meyers
Revco D.S. Inc.
Chesapeake, VA
October 25, 1993

(Continued on page 18)

What you always wanted to know but didn't know where to ask

(Resource List)

Inclusion of materials in this publication is for information only and does not imply endorsement by The Diabetics Division of the NFB.

New Diabetes Video

Living with Type II Diabetes, a new video, is designed to help people understand and live a better life with type II diabetes. It is available at a cost (check or money order) of $24.95 (shipping included) from: Living With Diabetes, P.O. Box 1928, Carlsbad CA 92018.

Diascan Partner Discount

The Diascan Partner is an eight-ounce audio output glucometer, which comes complete with adjustable over-the-shoulder tote bag, an earphone for private listening, and which features simplicity of operation and a clear, easy-to-understand voice. The system will announce its calibration settings, which can be changed as needed.

The Diascan Partner, manufactured by Home Diagnostics, Inc., comes with both print and cassette instructions. Although its suggested retail price is $399, Maxi-Aids Inc. is offering the Diascan Partner for $375.95. For further information contact Maxi-Aids Inc., 42 Executive Blvd., Box 3209, Farmingdale, NY 11735; telephone: 1-800-522-6294.

Test Strip Recall Notice

LifeScan Inc. is conducting a RECALL of ALL ONE TOUCH **Foil Wrapped** Test Strips. (ONE TOUCH **Vial-Packaged** Test Strips are NOT included.) Tests have indicated that the foil packaging of the recalled test strips may not consistently protect them from moisture — and moisture-damaged strips can give inaccurately LOW readings.

LifeScan asks you to discontinue using ALL **Foil-Wrapped** ONE TOUCH Test Strips, and to return them to LifeScan immediately. On receipt, LifeScan will ship to you, free of charge, an equivalent quantity of ONE TOUCH Vial-Packaged Test Strips as soon as possible.

LifeScan has set up a special **Recall Information Hotline** for you to call with any questions. This toll-free number is available 24 hours a day, every day: 1-800-600-7226.

Novolin Pen Warning

Novo Nordisk Pharmaceuticals, Inc., makers of the Novo Pen, Novolin Pen, and Novolin 70/30 insulin delivery devices, now state: "NONE OF OUR DEVICES ARE RECOMMENDED FOR USE BY BLIND OR VISUALLY IMPAIRED PERSONS WITHOUT SIGHTED AID."

The Novolin Pen Dial-A-Dose delivery device features an audible "click", and many people have used that feature to select an insulin dose by non-sighted means. Recently, problems have developed with the accuracy and reliability of the audible "click" prompt. The company states that the click may disappear due to wearing or breakage of an internal part of the device. "The click should NOT be used as an auditory signal to aid in setting the insulin dose when using the Novolin Pen," states Novo Nordisk. The user instructions state that all patients should use the dose visually displayed in the "dose indicator window" for accurate dosage setting.

The company has a recall/replacement program for owners of the gray-bodied Novolin Pens. However, all three Novolin insulin delivery devices are now recommended ONLY for use by the sighted. For further information, contact Novo Nordisk at: 1-800-727-6500.

Nutrition Hot Line

The National Center for Nutrition and Dietetics provides a Consumer Nutrition Hot Line. Staffed by registered dieticians, the service is available Monday through Friday, from 9 a.m. to 4 p.m. (Central time). Callers can listen to recorded messages, talk to the dieticians, request printed information, and locate registered dieticians in their own area. Some information is available in Spanish. Telephone: 1-800-366-1655.

Diabetic Men, Impotence, and How to Prevail

Sexual intercourse is a natural function, and when the male is unable to perform, it can be devastating for both the diabetic man and his partner. Erectile dysfunction has long been recognized as a negative element in human relationships. It is estimated that more than 50% of diabetic men will become impotent during their lives.

Most cases of impotence can be successfully treated. Diabetic men and their partners do have options. The article "Diabetic men, impotence, and how to prevail", which details many of these options, was published in the Spring 1992 issue of ***Voice of the Diabetic.*** For a free print copy, send a SASE, and for an audiocassette copy, send $1.00 (payable to National Federation of the Blind). Order from: Cheryl Smith, Chairwoman, NFB Diabetics Division Resource Library Committee, 7717 Eastern Avenue, Apt. B, Dallas, TX 75209; telephone: (214) 352-4974.

Cyclosporine Measuring Device

When the immunosuppressant/anti-rejection drug cyclosporine, used to prevent a transplant recipient's immune system from rejecting the new organ, first appeared in 1983, it was only available in liquid form. Now it is also available in 25mg and 100mg gel capsules, but some individuals prefer the liquid form.

There is a simple device with which a blind individual can, without sighted assistance, safely and reliably draw up accurate doses of cyclosporine. This device, a "measuring stopper sleeve," was developed by ***Voice*** editor Ed Bryant, who also perfected the measuring procedures to use it. A blind kidney transplant recipient himself, Editor Bryant has extensively tested his device, which has since been adopted by a number of transplant centers for use by blind transplant recipients.

For instructions, in print or on audiocassette, on how to construct and use the Cyclosporine Measuring Stopper Sleeve, please send S.A.S.E. to Cheryl Smith, Chairwoman, NFB Diabetics Division Resource Library Committee, 7717 Eastern Avenue, Apt. B, Dallas, TX 75209; telephone: (214) 352-4974. Please include $1 for the audiocassette.

Braille/Tape Food Exchange List

The "Exchange List for Meal Planning" is now available in Braille (83 Braille-written pages bound in a nice, durable, plastic cover) and on cassette.

This revision, the result of a joint effort of the American Diabetes Association and the American Dietetic Association, reflects today's food values and eating patterns. It continues to restrict fat but emphasizes high carbohydrate and fiber foods. Nutritive values have been increased for such foods as fruits and milk products, and for carbohydrate/starch exchanges. New additions include a list of free foods, exchange values of food combinations, and a list of foods for occasional use. There is also a glossary of nutritional terms and an index of foods.

Make tax deductible checks payable to: the National Federation of the Blind. Cost: Braille $10.00, and cassette $2.00. Order from: National Federation of the Blind, Materials Center, 1800 Johnson Street, Baltimore, MD 21230; telephone: (410) 659-9314.

Exercise Video

We have been asked to announce: CC-M Productions presents *Armchair Fitness*, a tape containing three twenty-minute exercise routines designed to be done in a chair. These workouts allow people who must exercise sitting down to obtain the benefits provided by a regular stretching and strengthening regimen. Cost is $39.95 plus $2.50 for shipping. For more information, or to order, contact: CC-M Productions, 8510 Cedar Street, Silver Spring MD 20910; telephone 1-800-453-6280.

Generic Test Strips

We have been asked to announce: Can-Am Care Corporation manufactures the Quick Check line of generic test strips. Its lineup of discount-priced strips now includes those for the Life-Scan One Touch blood glucose monitor. For further information, or to receive their "Questions and Answers" pamphlet, contact Can-Am Care Corporation at: 1-800-461-7448.

New Cookbook

R.A. Rapaport Publishing and Diabetes Self-Management Books announce the publication of *Healthy and Hearty Diabetic Cooking.* First published in Canada as *Choice Cooking: The Cookbook of the Canadian Diabetes Association*, the book has been completely revised to reflect the most up-to-date nutrition guidelines, the United States system of nutrition values, and the latest input from both the American Diabetes Association and the American Dietetic Association.

The book incorporates a number of special features. First, all recipes are designed for diabetic diets, with component substitutions to hold down fat, sodium, sugar, cholesterol, and total calorie count. Second, the book incorporates, as special aids, a chapter on using the microwave, one on techniques to prepare recipes in healthier ways, and one on using the ADA Exchange List (which is also included). The text is large-print, and the book is hardback, with a wipe-off cover.

The recipes run the gamut, with chapters on appetizers, soups, salads, poultry, fish, meats, vegetables, vegetarian main dishes, breads, desserts, preserves, sauces, and more! Throughout the text, it seems every effort has been made to render recipes as tasty and interesting as possible. Chicken with mozzarella and tomato sauce? Lentil-stuffed tomatoes? Ribbon cream torte? Blueberry cupcakes? Creamy vegetable soup? The only thing you *won't* find in *Healthy and Hearty Diabetic Cooking* is the old diabetes cookbook blandness.

Cost of the book is $23.95, plus $3.00 shipping and handling. Order from: Healthy and Hearty Diabetic Cooking, P.O. Box 11477, Des Moines, IA 50381-1477; telephone: 1-800-293-8638.

Letters to the editor (Continued from page 16)

Mr. Ed Bryant, President
Diabetics Division
National Federation of the Blind
Columbia, MO

Mr. Bryant:

I have recently become aware of your free quarterly publication called ***Voice of the Diabetic.*** Currently, I am a pharmacist with the Revco Drug chain, and I practice in Chesapeake, VA. I would like to take advantage of your offer to have this publication sent to my pharmacy free of charge. I have a large diabetic clientele and also am actively involved in diabetic education.

I also would like to receive this at my home if possible (just one sent quarterly would be great). If your organization has any other educational materials concerning diabetes, I would be interested in reviewing it and possibly have it sent to my pharmacy. Thank you very much for this offer, as I know it will greatly aid my patients.

Sincerely,
Andrew D. Meyers

• • •

Erma Antrim
Effingham, IL
October 30, 1993

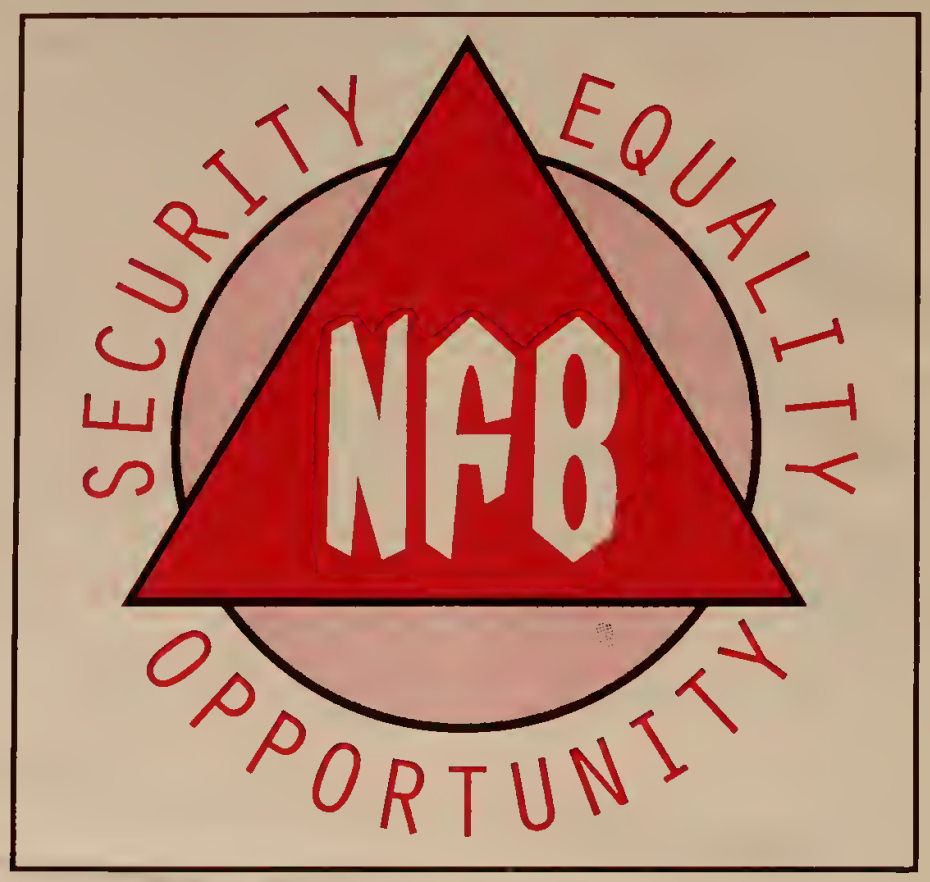
Voice of the Diabetic
Mr. Ed Bryant
Columbia, MO

Dear Mr. Bryant:

I just finished reading the Fall issue of the ***Voice,*** and I felt the urge to write and tell you how much I enjoyed it. I have been a member at large of the National Federation of the Blind for several years, and I really believe in our cause. I would like to help distribute the ***Voice*** to places of interest in my community, and I think I could give out about a hundred issues in this area. I know for a fact that this area needs some enlightening about blindness and independence. I also would like some copies of the other publication you named, "Diabetes, Complications, Options."

Thank you for your time ... and again I do think you are doing a great job.

Sincerely,
Erma Antrim



HCFA non-response to Diabetics Division inquiries

From the Editor: In May of 1993 I wrote to U.S. Health and Human Services Secretary Donna Shalala, bringing to her attention the difficulties blind diabetics and those losing vision often experience when trying to obtain Medicare reimbursement for purchase of glucometers. That letter was published in the Summer 1993 edition of ***Voice of the Diabetic.***

In July of 1993, Kathleen A. Buto, Director of Bureau of Policy Development, Health Care Financing Administration of the Department of Health and Human Services, delivered Secretary Shalala's official reply. Although Director Buto's letter (published in the Fall 1993 ***Voice****) contained much useful information, some questions were not clearly or completely addressed, and some information (such as fee schedules for Alaska and Hawaii) was entirely absent.*

On August 11, 1993, hoping for clarification of the above, I wrote back to Director Buto (this letter published in the Fall 1993 ***Voice****, and again below). I raised a number of specific points, and invited her to respond. As neither Director Buto nor any other representative of HCFA had communicated with us further, on November 10 I wrote again to HHS Secretary Shalala (this letter published below). As of press time, December 15, 1993, there has been no response from Secretary Shalala. I find this indeed unfortunate.*

Diabetics Division
National Federation of the Blind
Columbia, MO
August 11, 1993

Kathleen A. Buto
Director, Bureau of Policy
Development
Health Care Financing Administration
Dept. of Health and Human Services
Baltimore, MD

Dear Director Buto:

Thank you for your July 23, 1993 letter regarding Medicare policies and procedures for purchase of blood glucose monitors. The information you supplied helped clarify a number of points. Unfortunately, some questions remain unanswered. Alaska and Hawaii are entirely absent from your chart #1, "Medicare fee schedules." Where I mentioned examples of official misinformation or departure from the national fee schedule guidelines, you request "documentation." Please understand that the specific examples of incorrect reimbursement and HCFA nonconformity with HCFA guidelines were revealed in telephone conversations between Diabetics Division researchers and the appropriate Medicare authorities. It is very difficult to "document" erroneous information supplied over the telephone. In the state of Texas, where specific documentation *was* available, the Texas Commission for the Blind is required by law to maintain client anonymity.

In the matter of "weighted averages" for E0609, you state that the current fee schedule amount ($467.74) "exceeds the retail costs for one of the two available brands of blood glucose monitors with voice synthesizers." You do not address the fact that the national average cost for E0609, based on prices of both currently-available voice-assisted glucometers, is $522.50, $54.76 *above* the fee schedule ceiling. Why are blind diabetics still expected to lay out a far higher percentage of their own money than are the sighted for necessary medical equipment?

You state that the IR limit for E0607 is in the process of revision downward, reflecting decreasing prices for non-adaptive home blood glucose monitors. By the same standard, when can we expect an upward revision of E0609?

I fail to understand why an agency such as yours, mandated to be the "watchdog" over Medicare, shows such a marked reluctance to act. It would be a simple matter for you to test my assertions. The databases are yours; why depend solely upon client-supplied documentation?

The researchers for this project were all insulin-treated diabetics, members of The Diabetics Division of the National Federation of the Blind. On behalf of the Diabetics Division, I thank you in advance for your response.

Very truly yours,
Ed Bryant
President, Diabetics Division
National Federation of the Blind

cc: Donna Shalala, Secretary
Dept. of Health & Human Services

• • •

Diabetics Division
National Federation of the Blind
Columbia, MO
November 10, 1993

The Honorable Donna Shalala
Secretary of Health and Human
Services
Hubert H. Humphrey Building
Washington, DC

Dear Secretary Shalala:

I want to thank you for the cooperation you and your staff have provided toward our research into Medicare reimbursement for blood glucose monitors. As the welfare of many diabetics depends on accurate blood glucose monitoring, the issue of obtaining the proper equipment is of concern to us.

On May 20, 1993 I wrote my initial letter to you. I attempted to outline the issues and difficulties faced by many blind diabetics, and those losing vision, who attempt to obtain Medicare reimbursement for blood glucose monitors purchased under specifications EO609 and EO607.

On July 23, 1993 Kathleen A. Buto, Director of Bureau of Policy Development, HCFA, responded in your name. Her letter answered *some* of our questions, glossed over others, and totally omitted certain pertinent data such as the fee schedule figures for Alaska and Hawaii.

I replied to Director Buto on August 11, 1993 (copy enclosed), bringing to her attention the omissions and inconsistencies in her earlier text. At that time she was invited to respond. A copy of our reply was sent to you, and the entire exchange was published in ***Voice of the Diabetic,*** the national magazine of The Diabetics Division of the National Federation of the Blind.

As of this date, we have still not received any further response from Director Buto or any other representative of HCFA. As her initial response to my letter to you was prompt, surely this delay cannot be charged to bureaucratic inertia. Although this request for clarification and updating of a single HCFA specification (EO609) may seem minor, not a pressing issue in Washington, for many of our more than 75,000 readers it is very important indeed.

As before, we thank you in advance for your response. It is our intention to publish this letter, along with your reply, in an upcoming issue of the ***Voice.***

Very truly yours,
Ed Bryant
President, Diabetics Division
National Federation of the Blind

Food for thought

We invite blurbs and tidbit articles for inclusion in this column. Materials received may be edited and used as space permits. Products and services included in this column are for information only and do not imply endorsement by The Diabetics Division of the NFB.

New Insulin

Eli Lilly and Company, makers of Humulin, have developed a new rapid-acting insulin. This new product will offer several potential advantages over current "Regular" insulins, as it is designed to be far more quick-acting. First, it can be administered just before a meal rather than 30-45 minutes before, as is current practice. Second, as it absorbs very quickly, blood insulin levels will promptly increase as food is being absorbed, helping to hold down after-meal glucose levels. Third, the new insulin is of short duration, disappearing just a few hours after the meal, which should reduce the odds of a low blood sugar reaction between meals.

The new insulin has been the subject of simultaneous tests at 150 research centers. Results are awaited shortly. Stay tuned ...

NOTE: Information provided by *Michigan Diabetes Research and Training Center,* Ann Arbor, Michigan.

THANK YOU! THANK YOU!

To all of you who responded to our recent donations drive, an enormous THANK YOU! It costs more than $50,000 per year to publish ***Voice of the Diabetic,*** the principal communication tool of our Diabetics Division support and information network. As we offer subscription and Division membership without charge, and our advertising income covers only a portion of production costs, we depend on YOU to help us carry the message about blindness and diabetes to more diabetics, family members, health professionals, and individuals with an interest in the condition. As our circulation has now grown beyond 78,500, our need for your assistance grows more acute. Twice a year we send out requests for donations. To those of you who responded — Thank you again!

A Little Mixed Up

Just a line to say I'm living,
That I'm not among the dead,
Though I'm getting more forgetful
And more mixed up in my head ...

For sometimes I can't remember
When I'm standing at the stair
If I'm going up for something
Or I've just come down from there ...

And before the "fridge" so often
My poor mind is filled with doubt.
Have I put the food away,
Or have I come to take some out?

Then, those times when it is dark out,
With my night cap on my head,
I don't know if I'm retiring,
Or just getting out of bed ...

So if it's my turn to write you
There's no need in getting sore
I may think that I have written,
And don't want to be a bore ...

Just remember I do love you
And I wish that you were here,
There's the mailman at the corner
I must say goodbye, my dear ...

P.S. There I stood beside the mailbox
With a face so very red —
I should have mailed your letter
But I opened it instead ...

— (anonymous)

Noon Lions President Steve Smith (center) helps fellow club members Owen Jackson and Bill Dalzell package copies of the *Voice*.

Evening Lions Noel Summers, Frank Binkley, Father Eugene Robl, and Dr. Leo Basurto help *Voice* editor Ed Bryant prepare the paper for shipment to distributors.

Print or Tape?

Which ***Voice*** format is right for you? The ***Voice*** is offered, without charge, in both standard print format and 15/16 ips four-track audiocassette. If you are legally blind or physically handicapped, you may obtain the necessary tape player (music cassette players WON'T work) by contacting the National Library Service for the Blind and Physically Handicapped; telephone: 1-800-424-8567. If your vision is changing, and you find you need the tape, please contact us at the ***Voice*** editorial office, and we will arrange the switch. There is no charge to do so.

Many people who receive the ***Voice*** on tape also receive it in print, so it can be shared with family members, friends, and medical professionals. If you would like to receive the ***Voice*** in both formats (tape and print) simply let us know.

New State Diabetics Division

The National Federation of the Blind of Connecticut proudly announces the formation of a new Diabetics Division. Led by the capable John Yark, the new division should be a valuable resource for the diabetics of Connecticut and their families. Its board includes: John Yark, President; Robert Lynch, First Vice President; Bert Rivas, Second Vice President; Frank Puccinelli, Secretary; and James Terrell, Treasurer. Congratulations to the founding members of the National Federation of the Blind of Connecticut Diabetics Division, our newest state division!

Medicare Benefits Extended

The Omnibus Budget Reconciliation Act of 1993, recently signed by President Clinton, included a provision to extend Medicare immunosuppressive drug coverage to 18 months by January 1 of 1995 and three years by 1998. This should be good news for anyone considering an organ transplant.

Volunteers

Four times a year, when the ***Voice*** arrives hot off the presses, members of the Lions Clubs of Columbia put on their working clothes, roll up their sleeves, and go to work packaging the paper for our many distributors across the U.S. and world wide. They do this without charge, as a service project. In fact, for the last two issues, the Noon and Evening Lions worked a total of 40 man-hours! Participating were: Noon Lions Steve Smith, Owen Jackson, Bill Dalzell, Paul Schmidt, Bill Young, and J.O. Harris, and Evening Lions Frank Binkley, Dr. Leo Basurto, Dick Golden, Father Eugene Robl, Don Stewart, and Noel Summers. Lions Summers, Binkley, and Robl even came back for a second shift!

The fact that the ***Voice of the Diabetic*** can be offered free is in large part due to the fine efforts of volunteers such as these. Lions Club members — the Diabetics Division and our more than 78,500 readers send you their thanks.

For Sale:

Used, one-year-old MINIMED 504-S Insulin Pump. Excellent condition, $500. Call Patty at (314) 445-2030.

NFB Scholarship Program

The National Federation of the Blind will award a total of $71,500 in scholarships this year. Individual scholarship amounts range from $2000 to $10,000, and the competition is open to any legally-blind individual who will be a full-time student in fall 1994.

All scholarships are merit-based, and most are unrestricted. Entries will be judged on the criteria of academic excellence, financial need, and service to the community. The committee making the award decisions will be composed of blind citizens with distinguished academic and community backgrounds, from across the country.

The scholarship winners will be presented their awards at the 1994 convention of the National Federation of the Blind in Detroit, Michigan. Scholarship winners will also have all their expenses to attend the convention paid.

The National Federation of the Blind is an organization dedicated to creating opportunity for all blind persons. With more than 50,000 members, we are the largest organization of blind citizens in existence, and we award more scholarships to the blind than does any other group or organization. Recipients of Federation scholarships do not have to be members of the NFB.

Applications for the 1994 NFB Scholarship program must be received by March 31, 1994. We receive approximately 500 scholarship applications each year, so don't delay! Anyone interested may request as many application forms as needed from:

1. Peggy Pinder, Chairwoman; National Federation of the Blind Scholarship Committee; 814 4th Avenue, Suite 200; Grinnell, IA 50112; telephone: (515) 236-3366.
2. National Federation of the Blind Scholarship Committee, 1800 Johnson Street, Baltimore, MD 21230; telephone: (410) 659-9314.
3. All NFB Affiliate presidents.

Braille Chocolate Greeting Bars

We have been asked to announce: The Chocolate Experience, Inc. now offers chocolate bars with Braille greetings. The Braille is on the bar. Available messages are: "I Love You", "Happy Birthday", "Merry Christmas", "Happy Holiday", "Have a Nice Day", and "Thank You". The bars are available in semi-sweet, milk and white

(Continued on page 20)

Food for thought (Continued from page 19)

chocolate; and in sugar-free, milk and white chocolate (includes Mannitol as a sugar substitute).

For further information, contact: Judith Geva, The Chocolate Experience, Inc., 150-57 Bayside Avenue, Flushing, NY 11345; telephone: (718) 461-1873.

NOTE: The above products are made with chocolate, which is appropriate for diabetics only if their diabetes is under good control, and then only in moderation.

Tax Help

For assistance with completing your 1993 tax forms, you can telephone the Internal Revenue Service, toll-free: 1-800-829-1040.

National Convention

The 1994 Annual Convention of the National Federation of the Blind will take place July 1 through 7 at the Westin Hotel in Detroit, Michigan. The Westin is part of a gigantic complex called the Renaissance Center, which contains a shopping center and approximately 20 restaurants. The hotel has 1500 rooms, a 25,000 square foot ballroom, and an exhibit hall of similar size. Its central tower is 73 stories tall, and has a revolving restaurant on top. Room rates for the 1994 convention are: $38, singles; $43, doubles and twins; $45, triples; and $47, quads; plus tax.

During the annual convention of the NFB, our Diabetics Division will conduct two seminars. One will be a review of the latest adaptive equipment for blind diabetics, and the other will be the annual meeting of the Diabetics Division. Next issue, Spring 1994, the *Voice* will announce locations of dialysis centers in the Detroit metropolitan area.

Blind Wrestling

We have been asked to announce: The United States Association for Blind Athletes (USABA) Wrestling Nationals will be held March 26, 1994, in Indianapolis, IN. For further information contact USABA at: (719) 630-0422.

What's Coming Up!

The next issue of the *Voice* will include: an evaluation of talking blood glucose monitors, information about diabetic lower extremities and wound care, and many other personal and newsworthy stories.

Noninvasive Glucometers

Several years ago word arrived of a new glucose monitor type, one that could determine blood glucose levels without the need to pierce the skin and draw blood. The new technology makes use of the property of chemicals such as glucose to alter the wavelength of light transmitted through them. The device will project a bright light upon the skin, then electronic sensors will measure the altered beam and produce a blood glucose readout.

At least three versions of the noninvasive glucometer are currently in process of development. Sandia National Laboratories, in Albuquerque NM, has conducted successful clinical trials with a laboratory version of the instrument, but has yet to develop a marketable prototype. Futrex Inc., of Gaithersburg MD, has conducted field tests of their version, the "Dream Beam"; more are planned. Cascade Medical, of Eden Prairie MN, plans an extensive test campaign of their own.

At the conclusion of successful tests comes the long process of Food and Drug Administration approval. Researchers presently estimate a minimum of two years before the noninvasive glucometer becomes available. However, it is most definitely "on the way" and at some time in the not-too-distant future the lancet will take its place in the museum of medical curiosities.

Voice Distributors Needed

Since the *Voice* is now offered free, our Diabetics Division will provide extra copies to anyone wanting to help spread the word. We will gladly send from five to five hundred-plus copies each quarter to be used as free literature. Medical facilities can order as needed for patients. Individuals can usually place copies of the *Voice* in libraries, pharmacies, hospitals, doctor's offices, or other public locations.

Diabetes education is essential. Anyone who distributes the *Voice* will be helping people with diabetes, and their families, to learn about the disease and its ramifications; to learn that they have options; and that their world is far greater than whatever "limits" may be imposed by the disease. If you would like to help spread the word by distributing the publication, please contact: *Voice of the Diabetic*, 811 Cherry St., Suite 309, Columbia, MO 65201; telephone: (314) 875-8911.

ADVERTISERS

Effective advertising doesn't scream at its audience. It persuades. It sells. The key to cost-effective advertising is making your voice heard where an audience is already listening. *Voice of the Diabetic*, circulation 78,500+, offers such an outlet. Make *your* voice heard. For advertising information contact:

Voice of the Diabetic
Ed Bryant, Editor
811 Cherry Street, Suite 309
Columbia MO 65201-4892
(314) 875-8911

Subscription/Donation Form

The *Voice of the Diabetic* is a quarterly magazine published by The Diabetics Division of the National Federation of the Blind (NFB) for anyone interested in diabetes, especially diabetics who are blind or losing vision. It is an outreach publication emphasizing good diabetes control, diet and independence.

Donations are gladly accepted and appreciated. Contributions are not only tax deductible but are needed to keep the *Voice* and the Diabetics Division moving forward to help people with all aspects of diabetes.

Members of the NFB Diabetics Division enjoy priority services and unique benefits such as a continuous free subscription to the *Voice*, automatic access to committees covering all aspects of diabetes, free counseling concerning all facets of blindness and diabetes as well as access to diabetics who have experienced complications.

The *Voice* is free to any interested person upon request. Each subscription costs the Diabetics Division approximately $20 per year. To help defray publication expenses, members are invited, and nonmembers are requested, to cover the subscription cost.

To begin receiving the *Voice, please check one:*

[ ] I would like to become a member of the NFB Diabetics Division and receive the ***Voice of the Diabetic.*** (Members are entitled to special membership benefits.)

[ ] I would like to receive the ***Voice of the Diabetic*** as a nonmember. (Nonmembers are encouraged to pay the institutional rate of $20/one year; $35/two years; $50/three years.)

Send the *Voice* in (check one):

[ ] print [ ] cassette tape for the blind and physically handicapped (recorded at slower-than-standard speed of 15/16 IPS) [ ] both

Optionally check this box:

[ ] I would like to make (or add) a tax-deductible contribution of $ _____ to The Diabetics Division of NFB.

Please print clearly

Name _____

Address _____

City _____ State _____ Zip _____

Telephone (_____) _____

Send this form or a facsimile to:
Voice of the Diabetic, 811 Cherry St., Suite 309, Columbia, MO 65201

Please make all checks payable to:
NATIONAL FEDERATION OF THE BLIND